Sample Q&A with n of 1 author Glenn Sabin

INTRODUCTION

In 1991, at the age of 28, newlywed Glenn Sabin was given a diagnosis of Chronic Lymphocytic Leukemia (CLL), a type of cancer for which there was no cure. It was a death sentence.

He was told there were only two available options: an experimental bone marrow transplant, and "watchful waiting," both of which might give him more time; neither of which was a cure. But neither Glenn nor his wife Linda were comfortable with the idea of doing nothing. They decided to do something; that "something" had to be chosen carefully.

Glenn's response to his illness turned him from a terrified, powerless patient into an active participant in his own care. He became what he calls a "citizen scientist." Except for one clinical intervention—a surgery to address a symptom, not a curative cancer treatment—which was lifesaving, and which came with life-threatening complications, he chose to use only natural treatments. Now, twenty-five years later, he is totally cancer free.

Today, we will be introduced to Glenn's healing journey, which he writes about in his recently published book, n of 1: One Man's Harvard-Documented Remission Using Only Natural Medhods. His story will be of interest to every single person facing a diagnosis of cancer, or who knows someone facing such a diagnosis. This means everyone.

Q: Glenn, welcome. Please tell us how you felt when you were initially told you had chronic lymphocytic leukemia (CLL) and that there was no cure.

A: I was absolutely floored. It hit me out of left field. I was too young to have this "older person's disease." I went through the usual range of emotions: fear, anxiety, depression and dread.

Q: Your doctors recommended either an experimental bone marrow transplant or "watchful waiting," until your condition became acute. Why did you turn both of these options down in favor of "proactive observation"?

A: At the time, there was a 20% chance the experimental bone marrow transplant procedure would kill me. And if I did survive, we did not know if I would be "cured."

Watchful waiting was not an option, either. Watch for what, exactly? For the leukemia to come after me? No way! I needed to be proactive in the management of my disease—hence the term, "proactive observation." For me, being proactive involved gaining a better understanding of the biology of CLL, and learning how to take better care of my overall health. This meant drastically changing my lifestyle to support my health, through daily rigorous physical activity, dietary changes, drinking lots of water, and getting more sleep.

Q: **You mention a plant-based diet in your book. Tell us about your research into that kind of diet?**

A: That was in 1991, and the research at that time was actually quite sparse. We now know a lot more about plant compounds—phytochemicals—that are shown to be protective against cancer cells, especially for certain cancers that are considered to be "lifestyle-driven." There is clear consensus across the major cancer and health organizations that a healthy, primarily plant-based diet may significantly reduce cancer risk.

Q: **During your time of "proactive observation"—i.e., the 12 years between 1991 and 2003—you were able to keep your cancer at bay with your program of diet, exercise and lifestyle changes. What made you decide to add nutritional supplements to your program? What made you choose Ross Pelton? And what made you choose Irwin Rosenberg? Did these nutritionists play a role in your eventual shift to a more integrative approach?**

A: After my spleen was removed (mentioned earlier as the sole clinical intervention to address a symptom of the disease) in 1991, I went a dozen years before getting really sick. And for the record, there are many cases of people going five, 10, and even 20 years without treatment for CLL.

I was taking some supplements before I met Ross Pelton, but I wanted more expert input in this area. I read his book, Alternatives in Cancer Therapies, and within a couple of weeks, had an in-person consultation with him at his home.

Ross Pelton, like Irwin "Irv" Rosenberg, is a clinical nutritionist who is also a trained pharmacist. I worked with Pelton for five years. He was my first lifestyle medicine mentor and his influence was enormous. I moved on to Rosenberg, who I believed was approaching supplementation with cancer patients in a more innovative way.

Q: **How did your doctors respond to your decision NOT to follow their recommendations in 2003, the first time you became actively sick? Did you share your research with them?**

A: I did not find any research to give to my oncologists at the time I decided to refuse the combination of chemotherapy drugs and other agents they offered.

What they were offering was not a "curative" option. It was palliative. In other words, it would make me comfortable by lessening or even eliminating the side effects of the disease, which included low-grade fever, anemia, night sweats and fatigue. It would have been a Band-Aid. However, undergoing toxic treatments at that time would have desensitized the cancer cells to the same drugs that I might need in the future, in the likelihood my cancer returned and/or became worse.

But, my oncologists had a clear consensus that treatment should begin immediately. I declined. It was not a categorical refusal. I just needed more time to figure things out. In retrospect, I believe I made the correct decision.

I have had the same two oncologists, Drs. Bruce R. Kressel and Lee M. Nadler, for over 25 years. We have maintained a respectful relationship. No one has ever been "fired"—even when I refused conventional therapy. I have been very forthcoming with my approaches and what I was doing. We were each aware of what the research said: The standard of care in 2003 had zero chance of "curing" CLL.

Q: **How did you achieve your remarkable remission of leukemia without conventional therapy?**

A: I offer no conjecture in n of 1; I make no pronouncements, like specific cancer pathways that were targeted by precise interventions. We don't know; we may never know. I took a comprehensive approach; it was not reduced and randomized like a traditional controlled trial. In this case—at this level of scientific inquiry—outcomes do not prove causation.

Q: **You don't use the word "cure" in your book—have you cured yourself of CLL?**

A: For me, cure is not a useful or, in many cases, an accurate word. The notion that after five years without recurrent disease that someone is deemed cured is a bit disingenious.

A better approach to me is to declare someone disease-free—no evidence of disease based on the limitations of a blood test or PET/CT scan, which does not detect minute traces of cancer cells. (We each have cancer cells in our bodies. It's our immune system's ongoing job to seek out and destroy them.)

It's very difficult to eliminate cancer stem cells, where disease originates. Many people, being told they are "cured", may go right back to the bad habits and unhealthy lifestyle that may have contributed to their onset of disease. Many don't make necessary lifestyle changes upon diagnoses.

This is a primary reason why recurrent disease is so prevalent; it becomes harder to successfully treat once it recurs. Long-term durable remissions become elusive. I don't know if I am cured, but I am healed. Healed is different than cured. Sadly, not everyone can be cured, but a path to healing should be attainable for anyone affected by a life-limiting diagnosis, even if they ultimately succomb to the disease.

So I live my life as if I am healed. I am healed, but I do not let my guard down in terms of how I live my life. I still employ a comprehensive wellness program to stay as healthy as possible. I do the best I can in maintaining my wellbeing, but I will not use the word “cured” to describe my health today.

Q: Please talk about the significance/meaning of the title of your book: n of 1.

A: The letter “n” refers to the total number of subjects participating in a research (clinical) trial. For example, a study with 100 subjects has an “n” of 100, and a larger study with 1000 subjects has an “n” of 1000. An “n-of-1” trial, like mine, has only one subject. In my case, that subject was me. It was very informal but, to my mind, very significant.

The larger clinical trials, which the FDA requires before approving a drug, have an “n” of 1000+, and lead to treatment with a one-size-fits-all approach: one drug for every patient with the same type of cancer.

Q: Talk about the importance of your case study, which was published in 2015 in Cureus, which describes itself as “the medical journal for a new generation of doctors and patients.” And why do you think n-of-1 trials are increasingly important today?

A: My co-author, Dawn Lemanne, MD, MPH, an integrative oncologist, was the lead author on this case report. We felt it was important for my clinical case to undergo a peer review and become part of the medical literature. (The other four authors are Jeffrey D. White, MD, NIH/NCI director, Office of Cancer Complementary and Alternative Medicine (OCCAM); Johns Hopkins hematologist/oncologist Bruce R. Kressel, MD; my integrative oncology physician, Keith I. Block, MD; and Vikas P. Sukhatme, MD, ScD, Harvard Medical School.)

My peer-reviewed clinical case report can be accessed here: https://glennsabin.com/wp-content/uploads/2016/01/Glenn_Sabin_Cureus_case_report.pdf (It is titled “A Case of Complete and Durable Molecular Remission of Chronic Lymphocytic Leukemia Following Treatment with Epigallocatechin-3-gallate, an Extract of Green Tea.”)

As cancer treatment becomes more targeted and personalized to each patient’s unique disease, there will be smaller study sizes, and eventually, more n-of-1 trials. Whereas in the past these individual experiments (and single case reports) have been deemed more “anecdotal, ” over time I suspect n-of-1 trials like this will be become more prevalent, and not just for cancer. One day each person will be treated with a different treatment regimen, chosen specifically for him or her alone. No doubt this is the future of so-called precision medicine.

Q: Tell us about the conventional oncologists you were consulting? How did you choose them?

A: My conventional hematologists-oncologists are experts in my specific blood disorder, chronic lymphocytic leukemia (CLL). Bruce R. Kressel, MD is affiliated with Johns Hopkins. Lee M. Nadler, MD is at Harvard's Dana-Farber Cancer Institute. He is also a dean at Harvard Medical School.

It was important for me to work with the best academic minds. The various physicians I worked with and got consults from over the years, see lots of patients and study my particular form of cancer intensely. I encourage all cancer patients to be seen at an NCI (National Cancer Institute)-Designated Comprehensive Cancer Center. There are 47 such centers in the U.S. In almost all cases I believe it is important to get a second opinion from one of these centers of excellence. (To find an NCI-designated comprehensive cancer center near you, go to https://www.cancer.gov/research/nci-role/cancer-centers/find)

Q: **Were your conventional doctors curious about WHAT you were doing? And if so, do you think they told other CLL patients about your protocol?**

A: Yes, they have shown curiosity and I have shared freely. Some of their patients have found out about my case, and in some instances, have contacted me. The core of what my regimen includes—i.e., nutrition, exercise and stress reduction—is safe, effective, and is supported by the medical literature.

I must say, I've been quite fortunate to have such a mutually respectful relationship with my conventional oncologists.

Q: **Please talk about the integrative oncologists you consulted, and what is an integrative oncologist?**

A: An integrative oncologist is one who uses a combination of conventional cancer treatments and diagnostics, combined with complementary therapies that support the host—the patient—rather than therapies exclusively aimed at attacking the disease/tumor itself. Integrative oncologists use supportive methods—such as acupuncture, massage, exercise, and carefully chosen nutritional supplements—with an aim of minimizing the toxic side effects of conventional treatments.

Though I started working with nutritionists who were also licensed pharmacists years earlier, I did not enlist an integrative medicine or integrative oncology physician until 18 years after my diagnosis. The reason for this was two-fold: I was not aware that such specialists existed, and I was also doing well on my own up to that point.

Q: **In 2009, you engaged your first integrative oncology physician, Dr. Keith I. Block. Who was this doctor, and how did his recommendations differ from the recommendations of the conventional oncologists you originally worked with?**

A: When I started working with Dr. Block, considered the father of modern integrative oncology, we were able to fill some gaps in diet, and also approach recom-

mendations for dietary supplements in a more comprehensive, evidence-informed way—through various types of lab testing. We also reviewed every aspect of my lifestyle, an area my conventional oncologists never really asked about.

Q: **How did you meet Dr. Keith I. Block?**

A: I met Dr. Block at a conference in DC in 2009. His seminal book Life Over Cancer had just come out. I got to hear a lecture he presented along with his wife, Penny B. Block, PhD, a psychologist who works with cancer patients who are dealing with the stresses of their cancer diagnosis—such as anxiety and depression.

Much of their presentation centered on their clinical and educational approach at the Block Center for Integrative Cancer Treatment. I was thoroughly impressed with the comprehensiveness of their program, which integrates conventional cancer treatments such as chemotherapy and targeted drugs, as well as physical activity and nutrition.

I actually visited the Block Center before I became a patient there. I knew from the minute I stepped inside, that this was not your typical cancer clinic. The glass-enclosed kitchen was the first thing I saw—people getting cooking lessons and eating nutritious foods, while tethered to IVs. The Blocks spoke my language; this is what modern cancer care should look like.

Q: **How did you and Dr. Block decide which supplements you should take?**

A: Dr. Block conducted various labs to measure my nutrient levels, and other key areas connected to cancer growth, including inflammation, oxidative stress (from free radicals, which are counterbalanced with antioxidants) and other biomarkers believed to influence cancer growth.

Q: **Several times in your book, you state that you are a proponent of "evidence-based medicine," as opposed to "alternative" medicine. Please tell us the difference. And also, wasn't your use of nutritional supplements considered "alternative" at the time?**

A: When it comes to cancer treatment, I am a proponent of the standard of care—clinical treatment guidelines informed by science. If the standard of care is considered to be potentially curative, or otherwise the best proven approach to treat a specific disease, I tend to favor these guidelines for patient care. However, in my case, the standard of care was not curative, which is why I declined to follow my doctors' suggestions at that time.
Some people choose other, less researched approaches in lieu of the standard of care. That to me is "alternative medicine."

For example, Steve Jobs chose diet over a surgical procedure that, early on, might have prolonged his life. Job went with alternative medicine—primarily food-based therapy—and died.

I do not consider my integration of dietary supplements to be alternative medicine. Dietary supplements have been used for decades for nutrient deficiencies, to prevent or treat scurvy, and to protect the fetuses of pregnant woman, as examples. However, if I had chosen supplements instead of a proven, potentially curative conventional treatment for active and acute disease, I would consider that alternative medicine.

The fact is, if ibrutinib [the targeted kinase inhibitor discussed later in this interview] had existed back in 2003 and had been approved as a first line treatment, I might have taken it rather than extending my experiment. There's a good chance I would have used ibrutinib to hopefully reverse the symptoms of my disease, eliminate the bulk of leukemic cells in my body, and ideally achieve a durable remission.

Q: Tell us about your involvement with the Society for Integrative Oncology.

A: The Society for Integrative Oncology (SIO) was founded in 2003 by the acknowledged leaders—i.e., the pioneers—in the field of integrative oncology from Memorial Sloan Kettering Cancer Center, Dana-Farber Cancer Institute, and MD Anderson Cancer Center. Their mission was to create a forum to discuss the science of integrative approaches to cancer care.

I learned about the SIO from David Rosenthal, MD, a Harvard professor and past president of the American Cancer Society. After attending my first conference in 2009, the president of the organization, integrative oncologist Donald I. Abrams, MD, championed my inclusion to the board, and I was asked to serve for a three-year stint. It was a deeply rewarding experience.

SIO is an important organization, and the rigor of an academic foundation is much needed to help differentiate and verify all the so-called alternative, and integrative approaches to cancer patient care.

Q: What is the standard of care today for CLL? Has it changed since you were diagnosed in 1991? And if so, are people having better results today with the treatments?

A: Some of the same chemotherapy agents are still used for CLL treatment today, but there are also other types of drugs available since 1991, including monoclonal antibodies. The greatest advancement has come with a classification of drug called kinase inhibitors. This targeted agent has shown to be quite effective for certain types of CLL.

Though not a "curative" drug, ibrutinib is taken orally and can often keep patients' disease in a very manageable position over long periods of time. The downside is the cost of the drug, which I believe is currently about $10,000 per month.

There are several new and very promising drugs for CLL in the pipeline, and in early clinical trials.

Q: Tell us about the role of your co-author, Dawn LeManne, MD, MPH, and why you chose her to write n of 1 with you.

A: Although I do a lot of writing professionally for my consulting business, as well as my blog at glennsabin.com, it was critical for me to partner with a seasoned, respected medical oncologist. We needed to ensure the medical aspects of the content, including citations—the medical references to support the writing—were accurately captured and communicated to the reader. Together we poured over two decades of medical records and clinic notes. It also didn't hurt that Dr. LeManne is a truly excellent writer. She did the heavy lifting and made the book incredibly readable.

Q: You do professional cancer coaching, with most referrals coming from oncologists—what are the top three pieces of advice you give newly diagnosed clients?

A: During an initial 75-minute coaching consult, a lot of ground is covered. I break things up into manageable, implementable steps, to help avoid overwhelm. Keeping in mind the profound psychological impact a new cancer diagnosis presents, I emphasize:

- *The majority of diagnoses do not require immediate treatment; not necessarily the next day, week, or even month. Some oncologists and centers will encourage quick decision-making and a commitment from the prospective patient to be treated immediately. I encourage folks to take the necessary time to gather information to make informeed decisions.*

- *The importance of getting a second opinion from an expert clinician-scientist on their specific disease from an NCI-Designated Comprehensive Cancer Center.*

- *Lifestyle matters. I review a comprehensive intake and food journal to learn about how a client lives their life. I provide educational and informational support that encourages regular physical activity (that is most appropriate for where each client is currently at, condition-wise) which has great positive impact from both a psychological and physical standpoint. I encourage regular social interactions with friends and family, and a diet free of processed foods, sugary drinks and juices, swapping them for clean, whole foods and generous amounts of purified water.*

Though I do dig deeper than this during the first encounter, this is what I put the most emphasis on, while working hard to avoid overwhelming the client. The goal as a coach is to move cancer patient to action, not to create unnecessary stress and anxiety.

Glenn Sabin's Disease Journey—A Condensed Timeline

Part I

1991

- Onset of diagnosis
- Told disease is incurable; get affairs in order
- 7lb spleen removed
- Treatment choices: bone marrow transplant or "watchful waiting"
- Chose watchful waiting—coined "proactive observation"

Part II

1992

- Began lifestyle changes: diet, exercise, stress reduction, restorative sleep, pure filtered water, dietary supplementation

Part III

2003

- From 1991-2003 was symptom free; disease was "quiet"
- Early summer 2003, became very ill, with full force and effect of leukemia (24/7 low-grade fever, night sweats, anemia)
- Told by Harvard and Hopkins oncologists that immediate conventional treatment was necessary
- Refused conventional treatment because not curative
- Extended n-of-1 experiment in the hope of delaying conventional treatment
- Late summer 2003: Cleared bloodstream of leukemic cells—known as a partial remission; no evidence of disease from a clinical view; disease only seen in marrow (via pathological view)

Part IV

2009

- After a six-year partial remission, disease recurred in bloodstream
- Began working with new integrative medical team

2010

- Normalized blood for second time (see Part III, 2003) (continues on next page)

2012

- Full pathological remission: no evidence of disease in bloodstream or marrow (confirmed by biopsy done at Harvard)

2015

- Glenn's clinical case drafted by five co-authors, peer-reviewed, published in medical literature and indexed in PubMed.

2017

- Glenn remains in good health and laboratory tests continue to show no evidence of leukemia.